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# Preferences for involvement in treatment decision making of patients with cancer: A review of the literature

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## Summary

A systematic review of the literature about patients' preferences for involvement in cancer treatment decision making was conducted. Establishing preferences is important if the aim is to make health care more sensitive to the needs and expectations of each individual patient. Thirty-one papers were included in the review. Generalising from this literature is problematic because of limitations related to sample size, sample composition and methods used to assess preferences. Whilst we take cognizance of these limitations, research suggests that preferences vary considerably and that whilst most patients prefer a collaborative role, a significant minority prefer a passive or active role. Evidence about the association of factors such as age, gender, level of education, marital status, socioeconomic status and health status with preferences is inconclusive. Only a handful of studies investigated the degree of congruence between patients' role preferences and the actual role that they perceived they had played, which highlight that some patients experience a dissonance between the two. Similarly, few studies investigated the impact of this dissonance on patient anxiety or satisfaction with the treatment decision. We advocate more rigorous investigations before recommendations for health care professionals can be processed with confidence.

Keywords: Decision making; Treatment; Cancer; Involvement

## Introduction

Health and social care policy promotes the agenda of involvement by encouraging patients, careers and members of the public to adopt a greater

level of responsibility for and participation in health care, including, playing a much greater role in decisions affecting their own treatment and care ([Department of Health, 2003](#)). Medical ethics has emphasised the right of patients to be fully informed and to participate in treatment decision making, which is legislated for in some countries ([Guadagnoli and Ward, 1998](#)). The recent emphasis on patient involvement and autonomy in health care settings is indicative of efforts to promote a move away from a paternalistic form of care towards one of partnership between the medical profession and patients. This, in turn, reflects wider cultural tendencies that position patients as active consumers and citizens involved in making health care decisions.

There is a wealth of evidence related to treatment decision making for patients with cancer. This includes a significant amount of research about the use of decision aids ([Caress, 2000](#)) to facilitate decision making, but also a small but growing amount of literature related to other aspects of treatment decision making including research about the influence of patient involvement in treatment decision making on quality of life ([Andersen and Urban, 1999](#)), the impact of the media on treatment decision making ([Passalacqua et al., 2004](#)), the relationship of depression and anxiety to treatment decision making ([Petersen et al., 2003](#)), how married couples interact in reaching a treatment decision ([Boehmer and Clark, 2001](#)), patients' attitudes towards different treatment options ([Brundage et al., 2001](#)), decisional regret ([Davison and Goldenberg, 2003](#)), decision making in palliative care treatment ([De Haes and Koedoot, 2003](#)) and preferences for different types of treatment ([Soloman et al., 2003](#)).

Researchers have also investigated patients' preferences for involvement in treatment decision making. Establishing preferences for involvement in treatment decision making is important if the aim is to make health care more sensitive to the needs and expectations of each individual patient. Since patients are not a homogenous group, it cannot be assumed that they will all want to play an active or collaborative role in making decisions about their care. Thus, a shared decision-making process with doctors and patients involved in treatment decision making may be too simplistic of a model. This is why the process of health care professionals systematically finding out about patient preferences in relation to involvement in treatment decision making is seen as crucial.

As part of a larger systematic review of literature about the agenda of involvement in cancer care, a review of research about patients' preferences for involvement in treatment decision making was conducted ([Hubbard et al., 2007](#)). The review aimed to improve understanding of the role that patients with cancer want in relation to their treatment decision making, socio-demographic factors that influence role preference, the degree of congruence between patients' preferred and actual roles in treatment decision making, and the impact of role preferences on outcomes, such as patient satisfaction.

## Methods

### Type of review

This review was carried out using systematic methods to produce a narrative summary. We used systematic methods to search for literature, applied inclusion and exclusion criteria, appraised the quality of studies included, selected relevant data from the included studies for analysis and provided a narrative summary of these data.

### Searching for literature

All database searches ran from 1994 to 2004 inclusive. No language, geographical or methodological limits, was imposed on the results. The majority of hits were contained within the major and best-known health databases: AMED (Allied and Complementary Medicine), CINAHL, EMBASE, Evidence Based Medicine Reviews (Cochrane DSR, ACP Journal Club, DARE and CCTR), HMIC (Health Management Information Consortium), Medline and PsychINFO. A broad search including subject headings of the terms 'decision' (for example, decision making, choice, decision and decisional) and 'cancer' (for example, oncology, neoplasm and tumour) was employed. A cited reference search and free text searches were also conducted.

### Inclusion and exclusion of documents

The 279 papers were examined for potential inclusion in the review. Two members of the review team read abstracts and decided which papers to include in the review. Only research studies or reviews of literature about preferences for involvement in treatment decision making for cancer were included. Papers were included even if preferences for involvement in treatment decision making were only a part of the study. For example, if the study was also about preferences for information but contained findings on preferences for involvement in treatment decision making, it was included. Papers about role preferences for decision making about screening for cancer or genetic testing were not included because the focus of the review was on decisions related to treatment. Papers were included if the sample also included other groups of the population, such as patients with different diseases in addition to patients with a diagnosis of cancer, or groups of people that were related to patients with cancer for example, parents. There is a vast amount of literature about treatment decision making and the majority of papers excluded from the review were those that were about decision-making aids.

### Quality appraisal

Quality appraisal was conducted for all documents using the same criteria developed by [Dixon Woods et al. \(2005\)](#), as shown in [Box 1](#). Their criterion judges a paper on the clarity and explication of the aims and objectives of

the study, study design, methods and findings. Documents were rated 5 if all aspects of the study were clear, 4 if the method or analysis or sample were not clearly outlined or 3 if both the method or analysis and sample were poorly described.

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**Box 1** Quality appraisal criteria for empirical papers (Dixon Woods et al., 2005).

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1. Are the aims and objectives of the research clearly stated?
  2. Is the research design clearly specified and appropriate for the aims and objectives of the research?
  3. Do the researchers provide a clear account of the process by which their findings were produced?
  4. Do the researchers display enough data to support their interpretation and conclusions?
  5. Is the method of analysis appropriate and adequately explicated?
    - Documents were rated 5 if all questions were answered in the affirmative, 4 if the *method* or *analysis* or *sample* were not clearly outlined or 3 if both the *method* or *analysis* and *sample* were poorly described
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## Data analysis

One member of the review team extracted narrative data from each paper. Only narrative data related to preferences for involvement in treatment decision making, the factors that influence these preferences, the impact of preferences for involvement in treatment decision making on patient outcomes and the degree of congruence between patients' preferred and perceived actual role was extracted. Extracted narrative data were compared across each of the papers to identify key issues and summarise key points. Another member of the team read the papers to confirm that relevant narrative data had been extracted.

## Results

A total of 31 papers were included (26 from electronic database searches and

5 from cited references or journal searches), all of which received the highest quality appraisal rating. No literature reviews were found, thus all papers included in the review are research studies. Table 1 summarises the method employed, sample chosen and the key findings for each paper.

## Methods and sample

The 31 papers were compared by method and sample. The overwhelming majority of papers (24 in total) reported using

Author	Sample	Method	Preference
Barry and Henderson (1996)	7 Patients with heterogeneous cancers admitted to an oncology unit whose condition likely to be terminal within 6 months	Preferences scale—5 categories (Degner and Sloan, 1992)	<ol style="list-style-type: none"> <li>1. Preferences changed with the progression of the disease with patients becoming more active</li> <li>2. With the progression of the disease, there was a trend for patients to perceive that they did not play the role that they preferred with patients perceiving that they had a less active role than they desired</li> </ol>
Beaver et al. (1996)	150 Women newly diagnosed with breast cancer before surgery	<p>Interviews each time admitted to the unit (at least 5 times)</p> <p>Preferences scale—5 categories (Degner and Sloan, 1992)</p>	<ol style="list-style-type: none"> <li>1. Newly diagnosed women were more likely to want to play a passive role, whereas the benign women were more likely to want to play a collaborative role</li> <li>2. For the newly diagnosed group variables found to be weakly correlated with decision-making preferences were age, with older women preferring a more passive role, level of education, with women with lower levels of education preferring a more passive role and social class, with lower social classes preferring a more passive role</li> <li>3. For the benign group, age and social class were found to be weakly associated with decision-making preferences</li> <li>4. Marital status and family history of breast cancer were not associated with decision-making preferences for either group</li> </ol>

Table 1 (continued)

Author	Sample	Method	Preference
	200 Women with benign breast cancer as comparison group	1 Survey	
Beaver et al. (1999)	48 People diagnosed with colorectal cancer—from early diagnosis to many years from diagnosis	Preferences scale—5 categories (Degner and Sloan, 1992)	<ol style="list-style-type: none"> <li>1. 78.3% of people diagnosed with colorectal cancer preferred the doctor to make the treatment decisions compared to 52% of women diagnosed with breast cancer.</li> <li>2. 80% perceived that they had played a passive role in decision making compared to 60.7% of women diagnosed with breast cancer</li> <li>3. 60% of people diagnosed with colorectal cancer indicated that they had achieved their preferred role compared to 37.8% of women with breast cancer</li> </ol>
	Comparison with 150 women diagnosed with breast cancer in Beaver et al. (1996) (see above)	1 Survey	
Beaver et al. (2003) stage 1 of study	41 Patients with colorectal cancer 3–8 year post-diagnosis	3–8 Semi-structured interviews	<ol style="list-style-type: none"> <li>1. The majority of patients reported that they would not wish to actually actively make decisions about their treatment but they would want to be informed and involved</li> <li>2. Health care staff perceived that patients would want to be informed and involved but would not wish to assume responsibility of active decision maker</li> <li>3. Health care staff perceived that older patients were more inclined to be passive in relation to decisions about treatment</li> </ol>
	35 Health care staff		
Beaver et al. (2003) stage 2 of study	375 Patients with colorectal cancer	Attitudinal survey	<ol style="list-style-type: none"> <li>1. 88.3% wanted to share the decision-making process with doctors</li> <li>2. Women were more likely to prefer active decision-making roles, whereas age, social class did not influence preference</li> </ol>
Beisecker et al. (1994)	67 Physicians	Locus of authority in decision making—breast cancer scale	<ol style="list-style-type: none"> <li>1. Physicians, nurses and patients believed that a physician should be the dominant decision maker in breast cancer treatment decision making</li> <li>2. Physicians were less inclined than nurses or patients to support patient involvement</li> <li>3. Nurses were more inclined than patients or physicians to support patient involvement</li> </ol>

Table 1 (continued)

Author	Sample	Method	Preference
			<ol style="list-style-type: none"> <li>4. Surgical oncologists were more likely to support patient involvement than medical oncologists or radiation oncologists</li> <li>5. Patient age was not a significant factor in physician or nurse attitudes towards involvement</li> <li>6. Older age physicians and nurses compared to their younger counterparts were less likely to support patient involvement</li> </ol>
	94 Nurses 288 Female patients from a women's clinic—none diagnosed with breast cancer	1 Survey	
Bilodeau and Degner (1996)	74 Women with breast cancer who were within 6 months of diagnosis	Preferences scale—5 categories (Degner and Beaton)	<ol style="list-style-type: none"> <li>1. 43% preferred a passive role, 20% an active role, 37% a collaborative role</li> <li>2. 50% played the role that they preferred</li> <li>3. A significant difference existed in participants' assumed role by age category, with a greater proportion of older women assuming a passive role</li> </ol>
Bruera et al. (2001)	78 Patients attending an initial assessment in an tertiary palliative care outpatient clinic	Preferences scale—7 categories (Degner and Sloan, 1992)	<ol style="list-style-type: none"> <li>1. 63% of patients preferred a shared role, 17% a passive role and 30% an active role</li> <li>2. Physicians estimated that 38% of these patients would prefer a shared role, 32% a passive role and 30% an active role</li> <li>3. Agreement between patients and physicians with respect to perceived preferences for decision making occurred in only 38% of cases</li> <li>4. There was a trend for increased accuracy in physician perception of female patient's preferences as compared with male patients</li> <li>5. Physician perceptions of patient preferences were not more accurate in any of the age groups analysed</li> </ol>
	attending physician	1 Survey at end of consultation	
Bruera et al. (2002)	57 Women diagnosed with breast cancer attending their first outpatient consultation	Preferences scale—7 categories (Degner and Sloan, 1992)	<ol style="list-style-type: none"> <li>1. 23% of women preferred an active role, 67% a shared role and 11% a passive role</li> <li>2. Physicians estimated that 33% of these women would prefer an active role, 47% a shared role and 19% a passive role</li> </ol>



Table 1 (continued)

Author	Sample	Method	Preference
			3. Agreement between patients and physicians was observed in 42% of cases 4. The proportions of agreement between patients and physicians differed between categories of income and age, patients with a higher income and patients who were younger in age were more likely to be in agreement with their physicians 5. Age, education, income, race, employment status, marital status, current stage of disease and time since diagnosis did not influence patient stated preference 6. Patients who had received prior treatment were more likely to prefer a shared role and less likely to prefer a passive role in decision making compared with those patients who had received no prior treatment
Butow et al. (1997)	80 Adult outpatients with heterogeneous cancers	1 Survey at end of consultation  Preferences scale—5 categories (Sutherland et al.)	1. 36.3% favoured a collaborative role, 22.6% an active role, 41.3% a passive role 2. Patients attending for the first time were more likely to want greater involvement 3. Patients whose condition had recently worsened were more likely to want progressively less involvement in decision making 4. 31% of patients recorded the same preference between two consultations (3–6 months apart) 5. Ages, gender, marital status, type of cancer, prognosis or clinical condition were not related to change in involvement preferences between two consultations 6. Those attending for routine follow-up were more likely to move towards preferring more involvement
Davidson et al. (1999)	21 Patients with lung cancer attending out-patient clinic	Survey before and directly after 1 consultation and before their next consultation  Preferences scale—5 categories (Degner and Sloan, 1992)	1. 43% recalled preferring an active/ collaborative role, 57% recalled preferring a passive role

Table 1 (continued)

Author	Sample	Method	Preference
			2. 29% recalled a discrepancy between their preferred and actual roles, and recalled playing a less active role than desired 3. For the hypothetical example, 57% preferred an active/collaborative role, 43% desired a passive role
		2 Preference situations (1) Recall of their role (2) Hypothetical example	
Davison et al. (1995)	57 Men with prostate cancer diagnosed 0–6 months prior to study	Preferences scale—5 categories (Degner and Sloan, 1992)	1. 58% referred a passive role, 23% a collaborative role and 19% an active role 2. Age, education, marital status or stage of disease were not significantly related to preference for involvement in decision making 3. Men recently diagnosed (0–13 weeks) were significantly more likely to prefer a passive treatment decision-making role
		1 Survey	
Davison et al. (2002)	80 Couples (men with prostate cancer and spouses or partners)	Preferences scale—5 categories (Degner and Sloan, 1992)	1. 50% of men preferred to play an active role, 42.5% a collaborative role and 7.5% preferred a passive role 2. 51.3% of men preferred to play a collaborative role with their partners and 48.8% preferred an active role with their partner in making the final decision 3. 55% of partners preferred to play a collaborative role with their partner and 41.3% preferred a passive role with their partner making the final decision and 3.7% wanted to be active in making the decision for their husband
		1 Survey	
Davison et al. (2004)	87 Men scheduled for a diagnostic biopsy for prostate cancer	Preferences scale—5 categories (Degner et al., 1997)	1. 43% indicated a preference to take the lead in making treatment decisions, 47% to share decision making with their doctor, 10% of men reported preferring a passive role 2. Age, education and marital status had no significant effect on preference
		1 Questionnaire after biopsy	
Degner et al. (1997)	1012 Women with breast cancer irrespective of time from diagnosis	Preferences scale—5 categories	1. 22% preferred to select their own treatment, 44% preferred to select their treatment collaboratively with

Table 1 (continued)

Author	Sample	Method	Preference
			<p>their physician, 34% preferred their physicians to make treatment decisions on their behalf</p> <ol style="list-style-type: none"> <li>2. Younger women were more likely to prefer active or collaborative roles</li> <li>3. Women with more than high school education were more likely to prefer active or collaborative roles</li> <li>4. Women who were married were more likely to prefer active or collaborative roles</li> <li>5. Women whose first language was English were more likely to prefer active or collaborative roles</li> <li>6. Ethnicity was not a predictor of role preference</li> <li>7. 42% perceived that they achieved their preferred role</li> <li>8. Women who had the best chance of perceiving that they had achieved their preferred role were those who wanted the most passive role</li> </ol>
		1 Survey	
Dunsmore and Quine (1995)	51 (12–24 year olds) with past or present heterogeneous cancers	42-Item questionnaire including open and closed-ended questions	Although the majority would have preferred greater involvement, most did not complain too strongly about the physician making the decision for them
Gagnon and Recklitis 2003	118 Parents of paediatric oncology patients who were either receiving treatment or had completed treatment less than 2 years prior	Control preferences scale for pediatrics (adaptation of CPS, Degner and Sloan, 1992)	<ol style="list-style-type: none"> <li>1. 58.5% preferred a collaborative role, 28% an active role and 13.6% a passive role in treatment decision making</li> <li>2. The amount of time lapsed since the cancer diagnosis was not significantly related to preference for involvement in decision making</li> <li>3. Parent age, income and education were not significantly related to preference for involvement in decision making</li> </ol>
		1 Survey	
Gattellari et al. (2001)	233 Adult outpatients with heterogeneous cancers presenting to oncologist for first time (0–18 months since diagnosis)	Preferences scale—5 categories (Degner and Sloan, 1992)	<ol style="list-style-type: none"> <li>1. 45% preferred a shared role and 32% reported that they had attained this role</li> <li>2. 34% reported a match between preferred and perceived roles</li> <li>3. 29% perceived that they were more active than preferred and 37% participated to a lesser degree than desired</li> <li>4. Patients whose preferred and perceived roles matched experienced significantly greater decreases in anxiety from pre-consultation to immediate post-consultation when compared with</li> </ol>

Table 1 (continued)

Author	Sample	Method	Preference
			<p>patients whose involvement was greater or less than anticipated</p> <p>5. Those who preferred and perceived roles matched were more likely to be satisfied with the consultation. Patients who were less active than desired were least satisfied. Patients having greater input than preferred were as satisfied as those whose preferred and perceived roles matched</p>
		Survey prior to consultation and 2 weeks post-consultation	
Hack et al. (1994)	35 Women with breast cancer 2–6 months post-diagnosis	Preferences scale—5 categories (Degner and Sloan, 1992)	<p>1. 23% preferred active involvement and 57% preferred collaborative involvement, 20% preferred passive involvement</p> <p>2. Graduates from high school (American) were significantly more likely to prefer an active role than non-high school graduates who preferred a passive role</p> <p>3. Age, illness severity and treatment procedure were not significantly related to preference</p> <p>4. Active patients said that they wish to play such a role because it affords them control over their body, health and life</p> <p>5. Passive patients said that it was important to place faith and trust in their physicians because they possess the medical knowledge and expertise</p> <p>6. Active patients, and to a lesser extent passive patients, said that they believed that their physicians would like them to be more active in their medical care</p> <p>7. Several passive patients said that pressure to play a more active role was anxiety provoking</p>
		1 Survey	
Heyland et al. (2003)	135 Hospitalised adult patients at end of life with metastases (other diseases included)	Preferences scale—5 categories (Degner et al., 1997)	<p>1. With respect to preferred role in the scenario of a competent and incompetent patient, most respondents preferred some sharing on decisional responsibility. In the scenario of a competent patient, 32% preferred a shared role between the doctor and the patient, and in the scenario of an incompetent patient 33% preferred a shared role between the doctor, family and patient</p>

Table 1 (continued)

Author	Sample	Method	Preference
			<ol style="list-style-type: none"> <li>2. Age, education, employment status, marital status, living arrangements were not significantly related to preference</li> <li>3. Nausea and the effect of fatigue on ability of the patient to remember were significantly related to preference, with patients more likely to prefer a passive role</li> <li>4. In 34% of cases, patients wanted a more active role than physicians had estimated and in 34% of cases, patients wanted a more passive role than physicians had estimated</li> </ol>
		Survey pre- and post-consultation	
Janz et al. (2004)	101 Women newly diagnosed with breast cancer	Preferences scale—5 categories (Degner et al., 1997)	<ol style="list-style-type: none"> <li>1. Before their consultation, the majority of women (86%) preferred to either share their treatment decision (47%) or make the decision (38%) after input from the physician</li> <li>2. After the consultation, more women perceived that they made the decision after input from the physician than shared in the decision process</li> <li>3. It was more likely for women to experience a greater role in decision making than they originally preferred</li> <li>4. 38% of patients agreed with their physicians' assessment of who made the treatment decision</li> <li>5. Physicians perceived women taking a more limited role in the decision-making process than women perceived for themselves</li> <li>6. Women with a college degree were significantly more likely to prefer a more active role in the treatment decision</li> <li>7. Age, marital status, employment status and income were not significantly related to preference</li> <li>8. Psychological (anxiety, depression, self-efficacy) and social support factors (emotional, tangible, affectionate, and positive social interactions) were not significantly related to preferences for involvement in decision making</li> <li>9. A woman's preferred role was not associated with satisfaction with the treatment decision</li> </ol>

Table 1 (continued)

Author	Sample	Method	Preference
	8 Physicians	Survey pre- and post-consultation	10. Women who perceived playing a more active decisional role were more likely to report higher levels of satisfaction
Johnson et al. (1996)	76 Newly diagnosed women with breast cancer	Questionnaire—7 items	<ol style="list-style-type: none"> <li>1. 79.7% of women wanted a role in decision making, 73.6% wanted their physicians to make a recommendation</li> <li>2. According to patients' reports, physicians were equally likely to make treatment recommendations to both older and younger patients</li> <li>3. Younger women (under 52 years) were more likely to want their doctors to make a recommendation</li> </ol>
Keating et al. (2002)	1081 Women with breast cancer a minimum of 10 weeks after surgery	1 Survey Preferences scale—4 categories	<ol style="list-style-type: none"> <li>1. 64% of patients desired a collaborative role, 24% desired a very active role, 9% desired that the doctor presents his/her recommendations to them to accept or reject, 3% desired that the doctor decide</li> <li>2. 49% of women's reported actual role matched their desired role, 25% reported a less active role than desired and 26% reported a more active role than desired</li> <li>3. Women whose reported actual role matched their desired role remained most satisfied with their treatment choice</li> </ol>
Kraetschmer et al. (2004)	602—3 groups of outpatients (breast cancer, prostate cancer and fracture)	1 Survey post-surgery Problem-solving decision-making scale	<ol style="list-style-type: none"> <li>1. For current health condition vignette, 29.7% preferred a passive role, 67.3% preferred a shared role and 2.9% preferred an autonomous role</li> <li>2. For chest pain vignette, 50.1% preferred a passive role, 48.7% preferred a shared role and 1.2% preferred an autonomous role</li> <li>3. Those who preferred an autonomous role perceived themselves as more knowledgeable about current health condition than those preferring a passive role</li> <li>4. Those with high or blind trust in the physician were more likely to prefer a passive role, whereas those who preferred an autonomous role were</li> </ol>

Table 1 (continued)

Author	Sample	Method	Preference
			more likely to have moderate to low trust. Those who preferred a shared role exhibited high (but not blind) trust
		1 Survey post-surgery	
Lobb et al. (2001)	100 Women newly diagnosed with breast cancer and within 2–4 weeks of making adjuvant treatment decisions (pre- or post-surgery)	Preferences scale—5 categories (Cassileth et al., 1980)	<ol style="list-style-type: none"> <li>1. 54% wanted collaborative decision making, 23% preferred the doctor make the treatment decision, 23% preferred to make the decision themselves</li> <li>2. Younger women were more likely to prefer a collaborative role</li> <li>3. Education, marital status and occupation were not significantly related to preference</li> </ol>
		1 Survey	
Petrisek et al. (1997)	179 Recently diagnosed women with breast cancer (3–12 months since diagnosis)	1 Interview	<ol style="list-style-type: none"> <li>1. The likelihood of seeking out a second surgical opinion and consulting 3 or more physicians about treatment declined with age</li> <li>2. Older women reported being less confident than young patients concerning their ability to be assertive in treatment discussions with physicians</li> </ol>
Pyke Grimm et al. (1999)	58 Parents of children diagnosed with cancer (up to 1 year since diagnosis)	Preferences scale—control preferences for paediatrics (adaptation of CPS, Degner et al., 1997)	<ol style="list-style-type: none"> <li>1. At time of interview, 52% of parents preferred a collaborative role, 29% preferred a passive role, and 19% preferred an active role</li> <li>2. No relationship between age, gender, education, marital status and role preference</li> </ol>
Rothenbacher et al. (1997)	59 Hospitalised patients with advanced cancer and a defined palliative treatment goal	Preferences scale—5 categories (Degner et al., 1997)	<ol style="list-style-type: none"> <li>1. 73% of patients with cancer preferred a collaborative role, 9% preferred to make decisions on their own and 18% preferred the doctor to make the decision</li> <li>2. 49% of patients with chronic non-neoplastic disease preferred a collaborative role, 17% preferred to make decisions on their own and 34% preferred the doctor to make the decision</li> <li>3. Of persons from the general population, 56% of patients with chronic non-neoplastic disease preferred a collaborative role, 40% preferred to make decisions on their own and 4% preferred the doctor to make the decision</li> <li>4. Younger people were more likely to prefer an active role</li> </ol>

Table 1 (continued)

Author	Sample	Method	Preference
			5. Gender was not associated with any given preference 6. Co-morbidity of patients was not associated with any given preference 7. Marital status was not associated with any given preference 8. Employed patients were more likely to prefer more control in the decision-making process 9. Patients with extended education were more likely to prefer more control in the decision-making process 10. Physicians underestimated patients' preferences in 36% of cases because they rated patients as passive when they preferred an active or collaborative role or patients were rated as collaborative when they preferred an active role 11. Physicians overestimated patients' preferences in 28% of cases because they rated patients as active when they preferred a collaborative or passive role or rated them as collaborative when they preferred a passive role
	86 Hospitalised patients with chronic disease 115 Members of public Physicians of patients	1 Survey	
Stigglebout and Kiebert (1997)	55 Patients with various types of cancer receiving treatment at a radiotherapy clinic, 53 persons accompanying these patients	Preferences scale—5 categories (Degner and Sloan, 1992)	1. For each of the vignettes, a larger proportion of the companions than of the patients chose an active role 2. For the vignettes, no significant difference in preference was seen between the 2 patient groups suggesting that having a serious diagnosis such as cancer does not influence preference 3. For involvement in general, older respondents were more likely to prefer a passive role 4. For involvement in general and for the vignettes, women were more likely to prefer an active role 5. No association between education and preference was found
	53 Patients attending an out-patient clinic for follow-up surgery for a non-malignant condition, 36 persons accompanying these patients	1 Survey about involvement in general and using vignettes	
Wallberg et al. (2000)			1. 87% preferred to be collaborative in treatment decision making



Table 1 (continued)

Author	Sample	Method	Preference
	201 Women diagnosed with breast cancer within the last 18 months and who had undergone surgery	Preferences scale—5 categories (Degner and Sloan, 1992)	<ol style="list-style-type: none"> <li>2. Patients with high level of education were more likely to prefer an active role</li> <li>3. Most patients (72%) perceived that they played the role that they preferred, 20% wanted to be more active and 8% wanted to be more passive</li> </ol>
Wong et al. (2000)	101 Men diagnosed with prostate cancer at any stage attending patient oncology clinics	<p>1 Survey after seeing physician</p> <p>Preferences scale—3 categories (Cassileth et al., 1980)</p>	<ol style="list-style-type: none"> <li>1. Around 60% of men preferred shared decision making with their doctor at diagnosis, treatment and post-treatment</li> <li>2. Age, current disease status, currently on treatment or not, symptoms, marital status, children, education, retired, living alone or not, mental health, optimism or self-perception of general health and seriousness of condition did not influence stated preference</li> </ol>
1 Survey			

a preferences scale (Hack et al., 1994; Davison et al., 1995; Barry and Henderson, 1996; Beaver et al., 1996; Bilodeau and Degner, 1996; Butow et al., 1997; Degner et al., 1997; Rothenbacher et al., 1997; Stigglebout and Kiebert, 1997; Beaver et al., 1999; Davidson et al., 1999; Pyke Grimm et al., 1999; Wallberg et al., 2000; Wong et al., 2000; Bruera et al., 2001; Gattellari et al., 2001; Lobb et al., 2001; Bruera et al., 2002; Davison et al., 2002; Keating et al., 2002; Gagnon and Recklitis, 2003; Heyland et al., 2003; Davison et al., 2004; Janz et al., 2004), the overwhelming majority of which used the preferences scale developed by Degner and Sloan (1992), as shown in Box 2.

**Box 2** Control preferences scale (Degner and Sloan, 1992).

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- A I prefer to make the final selection about which treatment I will receive.
- B I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.
- C I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
- D I prefer that my doctor make the final decision about which treatment will be used, but seriously considers my opinion.
- E I will prefer to leave all decisions regarding treatment to my doctor.
- 

This scale categorises patients into one of three roles depending on the extent of their preferred involvement in treatment decision making:

- *Active*, where the patient themselves decides on which would be the most appropriate treatment option for themselves.
- *Collaborative* (sometimes described as shared), where the patient and the doctor jointly decide on the most appropriate treatment option and
- *Passive*, where the patient leaves the decision on the most appropriate treatment option to the doctor.

Most studies only included small numbers of patients and it was not possible from reading the paper to deduce whether or not these were representative of a larger population. Only nine studies recruited a patient group of 150 or more (Beisecker et al., 1994; Beaver et al., 1996; Degner et al., 1997; Petrisek et al., 1997; Wallberg et al., 2000; Gattellari et al., 2001; Keating et al., 2002; Beaver et al., 2003; Kraetschmer et al., 2004). The overwhelming majority of studies included adults and focused on adult preferences for involvement in treatment decision making.

**Table 2** Sample by cancer type.

Cancer type	Number of papers
Breast	11
Prostate	3
Colorectal	2
Lung	1
Heterogeneous	11
Pre-diagnosis/not cancer	3

One study elicited the preferences of teenagers and young adults (Dunsmore and Quine, 1995), one study focussed on the preferences of paediatric oncology patients (Gagnon and Recklitis, 2003) and one study focussed on the preferences of parents of paediatric oncology patients (Pyke Grimm et al., 1999).

Samples varied considerably by cancer type (Table 2). Most studies focussed exclusively on women with breast cancer (12 in total) (Beisecker et al., 1994; Hack et al., 1994; Beaver et al., 1996; Bilodeau and Degner, 1996; Johnson et al., 1996; Degner et al., 1997; Petrisek et al., 1997; Wallberg et al., 2000; Lobb et al., 2001; Bruera et al., 2002; Keating et al., 2002; Janz et al., 2004). One of these studies did not actually focus on a sample of patients with cancer but on the perceptions of oncologists, oncology nurses and patients attending a women's clinic (Beisecker et al., 1994). Most other studies focussed on a heterogeneous patient group with a mix of different cancers (11 in total) (Dunsmore and Quine, 1995; Barry and Henderson, 1996; Butow et al., 1997; Rothenbacher et al., 1997; Stigglebout and Kiebert, 1997; Pyke Grimm et al., 1999; Bruera et al., 2001; Gattellari et al., 2001; Gagnon and Recklitis, 2003; Heyland et al., 2003; Kraetschmer et al., 2004). One of these studies focussed on the parents of paediatric oncology patients with heterogeneous cancers (Pyke Grimm et al., 1999). Four studies focussed on patients with prostate cancer (Davison et al., 1995; Wong et al., 2000; Davison et al., 2002; Davison et al., 2004) with one study focussing on patients with prostate cancer pre-diagnosis (Davison et al., 2004). Two studies focussed on patients with colorectal cancer (Beaver et al., 1999, 2003), whilst one study focussed on patients with lung cancer (Davidson et al., 1999).

Study samples varied by time since diagnosis (Table 3). Nine studies included patients who had been newly diagnosed or were in the first six months post-diagnosis (Hack et al., 1994; Beaver et al., 1996; Bilodeau and Degner, 1996; Johnson et al., 1996; Lobb et al., 2001; Bruera et al., 2002; Davison et al., 2002; Keating et al., 2002; Janz et al., 2004), five studies included patients who were reaching 1–2 years post-diagnosis (Petrisek et al., 1997; Pyke Grimm et al., 1999; Wallberg et al., 2000; Gattellari et al., 2001; Gagnon and Recklitis, 2003) and four studies investigated the preferences of palliative patients (Barry and Henderson, 1996; Rothenbacher et al., 1997; Bruera et al., 2001; Heyland et al., 2003). It was difficult to

identify the time since diagnosis in 13 of the remaining studies since the sample either comprised a mix of different stages of cancer (Dunsmore and Quine, 1995; Beaver et al., 1996; Degner et al., 1997; Beaver et al., 1999; Wong et al., 2000; Beaver et al., 2003) or were unclear (Butow et al., 1997; Stigglebout and Kiebert, 1997; Davidson et al., 1999; Davison et al., 2002; Kraetschmer et al., 2004). The time since diagnosis was not relevant in two studies (Beisecker et al., 1994; Davison et al., 2004).

**Table 3** Sample by time since diagnosis.

Time since diagnosis	Number of papers
Newly diagnosed-first 6 months post-diagnosis	9
1-2 Years post-diagnosis	5
End of life/palliative care	4
Various/not known/not applicable	13

#### Preferences for involvement in treatment decision making

A total of 20 studies used Degner and Sloan (1992) (Box 2) preferences scale to categorise patients' preferences for adopting an active, passive or collaborative role in treatment decision making. In 11 of these studies, involving a range of patients with different cancer types and at different stages following diagnosis (including children and patients in the palliative stages of care), the majority of patients clearly expressed a preference for a collaborative role in treatment decision making (Hack et al., 1994; Degner et al., 1997; Rothenbacher et al., 1997; Wallberg et al., 2000; Bruera et al., 2001; Gattellari et al., 2001; Bruera et al., 2002; Gagnon and Recklitis, 2003; Heyland et al., 2003; Davison et al., 2004; Janz et al., 2004). In six studies, the majority of patients expressed a preference for a passive role (Bilodeau and Degner, 1996; Butow et al., 1997; Beaver et al., 1999; Davidson et al., 1999; Pyke Grimm et al., 1999; Hinds et al., 2000). These studies involved patients with a diagnosis of breast, lung, colorectal or prostate cancer at different stages following diagnosis. Beaver et al. (1996, 1999) identified that although both patients with breast or colorectal cancers in these studies expressed a predominant preference for a passive role, more patients in the colorectal cancer group were likely to prefer a passive role than those in the breast cancer patient group. In a later study amongst patients with colorectal cancer only (n = 375); however, Beaver et al. (2003) identified that a greater number of patients expressed a preference for a collaborative role in treatment decision making. One study of parents of paediatric oncology patients found that the majority of parents preferred a collaborative role (Pyke Grimm et al., 1999). There were only three studies in which the majority of patients expressed a preference for an active role in treatment decision making (Barry and Henderson, 1996; Stigglebout and Kiebert, 1997; Davison et al., 2002).

## Factors affecting patients' preferences for involvement

A number of studies have researched the associations between patients' preferences for involvement in treatment decision making and age (16 in total) (Beisecker et al., 1994; Hack et al., 1994; Davison et al., 1995; Beaver et al., 1996; Bilodeau and Degner, 1996; Butow et al., 1997; Degner et al., 1997; Petrisek et al., 1997; Rothenbacher et al., 1997; Pyke Grimm et al., 1999; Wong et al., 2000; Lobb et al., 2001; Bruera et al., 2002; Beaver et al., 2003; Heyland et al., 2003; Davison et al., 2004), gender (4 in total) (Butow et al., 1997; Rothenbacher et al., 1997; Pyke Grimm et al., 1999; Beaver et al., 2003), race/ethnicity (2 in total) (Degner et al., 1997; Bruera et al., 2002), level of education (15 in total) (Hack et al., 1994; Beaver et al., 1996; Davison et al., 1995; Degner et al., 1997; Rothenbacher et al., 1997; Stigglebout and Kiebert, 1997; Pyke Grimm et al., 1999; Lobb et al., 2001; Wallberg et al., 2000; Wong et al., 2000; Bruera et al., 2002; Gagnon and Recklitis, 2003; Heyland et al., 2003; Davison et al., 2004; Janz et al., 2004), marital status (12 in total) (Davison et al., 1995; Butow et al., 1997; Degner et al., 1997; Rothenbacher et al., 1997; Beaver et al., 1999; Pyke Grimm et al., 1999; Wallberg et al., 2000; Lobb et al., 2001; Bruera et al., 2002; Heyland et al., 2003; Davison et al., 2004; Janz et al., 2004), employment status (5 in total) (Rothenbacher et al., 1997; Lobb et al., 2001; Bruera et al., 2002; Heyland et al., 2003; Janz et al., 2004), socioeconomic status (2 in total) (Beaver et al., 1996, 2003), level of income (3 in total) (Bruera et al., 2002; Gagnon and Recklitis, 2003; Janz et al., 2004), type or stage of cancer (3 in total) (Davison et al., 1995; Wong et al., 2000; Bruera et al., 2002) and patients' health status (5 in total) (Barry and Henderson, 1996; Butow et al., 1997; Hinds et al., 2000; Wong et al., 2000; Bruera et al., 2002). These findings are summarised in Table 1.

Briefly, 11 studies did not identify an association between age and role preferences (Beisecker et al., 1994; Hack et al., 1994; Davison et al., 1995; Butow et al., 1997; Pyke Grimm et al., 1999; Wong et al., 2000; Bruera et al., 2002; Beaver et al., 2003; Heyland et al., 2003; Davison et al., 2004; Janz et al., 2004). Five studies, however, including three studies involving patients with breast cancer and one study involving patients receiving palliative care, reported that younger people were more likely to prefer a collaborative or active role in decision making (Beaver et al., 1996; Bilodeau and Degner, 1996; Degner et al., 1997; Rothenbacher et al., 1997; Lobb et al., 2001). In contrast, one study including 76 women with breast cancer reported that younger women were more likely to want their doctors to make a recommendation (Johnson et al., 1996). Three studies reported no association between gender and role preference (Butow et al., 1997; Rothenbacher et al., 1997; Pyke Grimm et al., 1999), whereas one study found that women were more likely to prefer an active role (Beaver et al., 2003). There were no studies which identified an association between race/ethnicity and role preference (Degner et al., 1997; Bruera et al., 2002) and between level of income and role preference (Bruera et al., 2002; Gagnon and Recklitis, 2003; Janz et al., 2004). One study reported an

association between employment status and role preference, with employed patients wishing a more active role in their treatment decision making (Rothenbacher et al., 1997). A total of six studies, primarily involving patients diagnosed with breast cancer, have reported an association between level of education and role preference, finding that those with a higher level of education prefer a collaborative or active role in their treatment decision making (Hack et al., 1994; Beaver et al., 1996; Degner et al., 1997; Rothenbacher et al., 1997; Wallberg et al., 2000; Janz et al., 2004). On the other hand, eight studies have reported no such association between education and role preference (Davison et al., 1995; Wong et al., 2000; Bruera et al., 2002; Stigglebout and Kiebert, 1997; Keating et al., 2002; Gagnon and Recklitis, 2003; Heyland et al., 2003; Davison et al., 2004).

Marital status was found to be associated with role preference in eight studies, with married people being more likely to prefer an active role in their treatment decision making (Davison et al., 1995; Butow et al., 1997; Rothenbacher et al., 1997; Wong et al., 2000; Lobb et al., 2001; Bruera et al., 2002; Heyland et al., 2003; Janz et al., 2004). These studies included a range of patients with different cancer types, such as breast and prostate cancer, and at different stages in their cancer journey, including those newly diagnosed, to those in the palliative stages of their disease. Four studies, including one involving more than 1000 women with breast cancer (Degner et al., 1997) did not identify an association between marital status and role preference (Beaver et al., 1996; Pyke Grimm et al., 1999; Davison et al., 2004). Two studies, in patients with breast or colorectal cancers, investigated the association between socioeconomic status and role preference (Beaver et al., 1996, 2003). Whilst the study in patients with breast cancer (Beaver et al., 1996) identified that lower socioeconomic status was associated with a passive role, there was no such association found amongst patients with colorectal cancer (Beaver et al., 2003).

Three studies investigated the association between patients' type or stage of cancer and role preference, but found no association (Davison et al., 1995; Wong et al., 2000; Bruera et al., 2002). Three studies noted an association between declining health status or the experience of cancer-related side effects and role preference (Barry and Henderson, 1996; Butow et al., 1997; Hinds et al., 2000). One study (Butow et al., 1997) found that patients whose condition had recently worsened were more likely to want progressively less involvement in decision making, whilst another small-scale study (Barry and Henderson, 1996) (n = 7) found that patients whose condition had worsened were more likely to prefer an active role in decision making. A team of researchers (Hinds et al., 2000) who investigated the preferences of patients in the palliative stages of their disease reported that nausea and the effect of fatigue on the ability of the patient to recall events, were significantly related to role preference, with more patients preferring a passive role. Two studies reported no association between health status and role preference (Wong et al., 2000; Bruera et al., 2002).



## Degree of congruence between role preference

A total of eight studies investigated the degree of congruence between patients' role preferences and the actual role that they perceived they had played in treatment-decision making (Table 4). These studies mainly focussed on patients with breast cancer (Bilodeau and Degner, 1996; Degner et al., 1997; Beaver et al., 1999; Wallberg et al., 2000; Keating et al., 2002) although one of these studies also incorporated patients with colorectal cancer (Beaver et al., 1999). Two studies focussed on patients with one of a range of cancer types (Barry and Henderson, 1996; Gattellari et al., 2001) and one study focussed on patients with lung cancer (Davidson et al., 1999). The findings from these studies revealed that there were no studies in which all patients who participated attained their role preference. In fact, in four of these studies, less than 50% of patients who participated attained their role preference (Degner et al., 1997; Beaver et al., 1999; Gattellari et al., 2001; Keating et al., 2002). However, researchers in one study (Beaver et al., 1999) reported that 60% of the patients who had been diagnosed with colorectal cancer attained their role preference (12% more than in the breast cancer patient group in the same study) and a total of 72% of patients with breast cancer in another study (Wallberg et al., 2000) perceived that they played the role that they preferred. Three studies (Barry and Henderson, 1996; Bilodeau and Degner, 1996; Degner et al., 1997) investigated which patients were most likely to achieve their role preferences. One team of researchers (Degner et al., 1997) identified that those women who had perceived that they had achieved their role preference were those who had preferred a passive role, whereas in another study (Bilodeau and Degner, 1996), the researchers found that agreement was most evident between women who preferred an active role and who perceived that they had indeed achieved this role. A small scale pilot study (Barry and Henderson, 1996) of palliative patients (n =7) found that discrepancies between role preferences and role attainment increased with the progress of the disease with patients perceiving that they had played a less active role than preferred.

**Table 4** Percentage of patients attaining role preference.

Author	Cancer type	Percentage of patients
Barry and Henderson (1996)	Heterogeneous	Not stated as percentage
Bilodeau and Degner (1996)	Breast	50%
Degner et al. (1997)	Breast	42%
Beaver et al. (1999)	Breast	37.8%
	Colorectal	60%
Davidson et al. (1999)	Lung	71%
Wallberg et al. (2000)	Breast	72%
Gattellari et al. (2001)	Heterogeneous	34%
Keating et al. (2002)	Breast	49%

Four studies also investigated the degrees of congruence between patients'

own role preferences and their physicians of these preferences (Rothenbacher et al., 1997; Pyke Grimm et al., 1999; Bruera et al., 2001; Heyland et al., 2003). In all of these studies, agreement between patients and physicians, with respect to decision-making preferences, occurred in less than 50% of cases (Rothenbacher et al., 1997; Pyke Grimm et al., 1999; Bruera et al., 2001; Heyland et al., 2003). One team of researchers (Bruera et al., 2002) also identified that the degree of congruence between patients' and physicians' perceptions differed between categories of income and age, with patients of a higher income status and patients who were younger being closer to physicians' perceptions of their patients' decision-making preferences.

### Impact of role preferences on patient outcomes

Three studies investigated whether the extent to which patients actually achieved their role preference in treatment decision making impacted upon patient outcomes, such as level of anxiety experienced and satisfaction with the consultation (Heyland et al., 2000; Keating et al., 2002; Janz et al., 2004). One team of researchers (Heyland et al., 2000) found that patients who attained their role preference (34%) experienced significant decreases in anxiety from pre-consultation to immediate post-consultation, when compared with those whose involvement was less than anticipated. They also identified that patients who attained their role preference were more likely to be satisfied with the consultation and patients who were less active than desired were more likely to be less satisfied (Heyland et al., 2000). Researchers (Keating et al., 2002), in a study involving over 1000 women with breast cancer, also reported that patients who attained their role preference (49%) were more likely to be satisfied with the treatment decision-making process. Another study (Janz et al., 2004), however, found that role preference in women with breast cancer ( $n = 101$ ) was not associated with greater levels of satisfaction with the treatment decision itself, but women who perceived that they had played a more active role in decision making were more likely to feel higher levels of satisfaction in general.

### Discussion

#### Methodological concerns

Despite the growing abundance of research in relation to preferences for involvement in treatment decision making amongst patients with cancer, there are a number of methodological limitations of this body of work worth noting. In particular, generalising from the 31 studies included in this review is problematic because of small sample sizes, the inability to decipher from reading these papers whether or not the sample is representative of a wider population and the wide variation in the characteristics of the study samples.

Sample sizes were small in the majority of studies included in this review



(only nine studies had recruited a patient group of 150 or more). This is a cause of concern for those studies that used statistical techniques to investigate relationships and correlations between variables (for example, preference for involvement in treatment decision making with age), since samples of less than 100 can produce misleading results. It is also impossible to assess from what was written in some papers about sampling and recruitment whether or not those patients sampled were representative of a larger group of the population. Yet, without this information it is not possible to assess whether findings can be generalised beyond the study sample. Moreover, most studies have either focussed on the preferences of women with breast cancer or have included a heterogeneous group of a mix of cancer types. The findings from studies focussing on patients with breast cancer, therefore, represent only a small subset of patients with cancer, whilst the inclusion of heterogeneous groups makes it impossible to determine how cancer type, stage of cancer, and indeed, treatment options, influence patients' preferences for involvement in treatment decision making. Furthermore, little research has investigated the extent to which patients' preferences vary by prognosis and severity of illness. These factors are often not considered as part of a systematic sampling strategy and hence, generalising the findings from a study of preferences for one group of patients with a specific type of cancer to another group of patients is inappropriate. Finally, largely missing from this body of research is investigations of preferences of palliative patients and those of teenagers and young people.

Another reason why caution must be used in generalising from this body of evidence is because some studies examined patients' perceptions of preferences for involvement in treatment decision making based on their recollections of the decision process. This may have been several months after the actual event, whereas other studies asked patients to recall their preferences much closer to the decision-making event. Other studies did not ask patients to recall, but rather used hypothetical examples. Although studies have varied in their sampling strategies, with some recruiting newly diagnosed patients, and others recruiting patients who may be considered in the survivorship period, or indeed in the palliative stages of their disease, it is not known the extent to which patients' perceptions of their preferences for involvement is dependent on when they are asked to recall their preferences.

The predominant method for assessing patients' preferences for involvement in treatment decision making has largely involved the use of a preferences scale (Box 2). The reliability and validity of these scales is questionable, however, since a study by Entwistle (2001) found that it is difficult for patients to select an appropriate role description using such a scale. Furthermore, patients may choose conflicting role descriptions from the scale and patients may choose descriptions which may not necessarily correspond with their narrative descriptions about how their treatment decisions were made (Entwistle, 2001). Concern about a lack of consensus

amongst patients and health care professionals about what the concepts of participation and involvement actually mean further compounds the problem with the reliability and validity of these scales. Subsequently, further research should investigate these points in conjunction with the use of these types of scales.

### Summary and gaps in evidence

Although cross comparison of published studies about patients' preferences for involvement in treatment decision making is problematic due to the limitations discussed above, the 31 studies included in this review show that patients' preferences vary quite considerably. While most patients are likely to prefer a collaborative role, a significant minority prefer a passive role, followed by those who prefer an active role. Some studies have found that this minority can be quite substantial suggesting that making assumptions that patients wish to assume responsibility for treatment decision making is not necessarily wise.

Some studies have investigated the association between factors such as, age, gender, race/ethnicity, education, level of income, marital status, employment status, socioeconomic status, type and stage of cancer and patients' health status with role preferences in treatment decision making. However, the evidence to date is contradictory, meaning that the extent to which these factors influence patients' preferences for involvement is unclear. Given the inconclusiveness of this evidence, it is not possible to predict which patients will prefer passive, active or collaborative roles in treatment decision making. Perhaps it is not surprising therefore, that physicians are not able to accurately predict patients' preferences in most cases and there is no simple formula that they can use to facilitate accurate prediction of these. It seems, on balance, that predicting patients' preferences may, therefore, be a wasted effort.

Only a handful of studies have investigated the degree of congruence between patients' role preferences and the actual role that they perceived themselves to have played in treatment decision making. This body of research suggests that whilst some patients do attain their role preference, there are many others who do not. Why some attain their role preference and others do not, however, has not been considered in any great detail. Furthermore, given the small numbers of studies that have investigated the impact of role preferences on outcomes such as, anxiety and patient satisfaction, it is not possible to confirm with certainty whether attaining role preferences, particularly active or passive roles, actually impacts on patients' outcomes. It seems naive to assume therefore, that all patients will benefit from active involvement in treatment decision making.

None of the studies included in this review examined patients' preferences for involvement in treatment decision making over time. Yet, patients'

preferences may not be a static or one-off event but instead, may be a dynamic and longitudinal process for the following reasons; patients may prefer to adopt a passive role within the first few months following diagnosis, but prefer a more active role during the course of their illness or vice versa, preferences may change in relation to the stage of their disease and the seriousness of their condition, and preferences may vary according to the specific treatment decision that patients are required to consider. Whether and how preferences change over the patient journey warrants further research.

### Limitations of the review

Whilst we are confident that the electronic searches identified relevant studies we did not give enough time to hand searching in all relevant journals, which means that some relevant papers may have been overlooked. Moreover, this review does not represent the complete body of research since we only included papers published between 1994 and 2004 and there has been some seminal research about preferences for involvement in treatment decision making carried out prior to 1994 ([Cassileth et al., 1980](#); [Degner and Sloan, 1992](#)). Finally, whereas this is a narrative review of the evidence, which is a descriptive account of the data about preferences for involvement in treatment decision making, a meta-analysis of some of the studies included here, particularly those that have similar samples and which use the same preferences scale, could also provide some useful insight about patients' preferences.

### Conclusions

Changes in societal attitudes towards patient involvement in treatment decision making coupled with a much more consumerist and citizenship approach to health care is likely to affect medical practice. Those recommending increasing involvement of patients in treatment decision making have asserted that most patients prefer a collaborative role and that this leads to improved satisfaction with the consultation and decision-making process. Yet, this assertion is not confirmed by most of the empirical work conducted thus far. Evidence about patients' preferred level of involvement in treatment decision making, the factors that influence their level of involvement, the degree of congruence between their preferred and actual roles in treatment decision making and the impact of their involvement on patient outcomes is not compelling. More rigorous investigations are required before recommendations for health care professionals can be processed with full confidence. It is with this proviso in mind that we conclude by making the following recommendations for health professionals in relation to patients' involvement in treatment decision making which stand in the face of the limited current evidence base.

Given that patients vary in their preferences for involvement in treatment decision making, it is important that health care professionals identify

individual decision-making preferences, rather than advocate participation or non-participation for all patients. To deliver patient-centred care that privileges the needs of the patient above those of the system, health professionals should assess each patient individually and acknowledge that preferences are likely to change over time and with the influence of many factors. Thus, assessing preferences for involvement is not a onetime event but rather, a process that should be conducted throughout the duration of the patients' cancer journey. Finally, there is no formula for predicting patients' preferences and so possibly, the easiest way to find out about patients' preferences for involvement in treatment decision making is simply by asking them.

#### Conflicts of interest

There are no conflicts of interest.

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